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ORIGINAL ARTICLE

Communicating cancer and its treatment to Australian Aboriginal and Torres Strait Islander patients with cancer: a qualitative study

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Abstract

Purpose To investigate the successful strategies of health workers who support and regularly communicate with Aboriginal and Torres Strait Islander people about cancer and its treatment.

Methods Semi-structured interviews were conducted face-to face or via telephone and audio-recorded with twenty-three health professionals (medical and radiation oncologists, oncology nurses and Aboriginal Health Workers), 5 identifying as Aboriginal or Torres Strait Islander in the Northern Territory and South Australia. When data saturation was reached, thematic analysis using a bottom up, essentialist/realist approach was used.

Results Six themes emerged. (1) *Create a safe environment, engender trust and build rapport.* This involves considering the physical environment and allowing time in interviews to establish a relationship. (2) *Employ specific communication strategies* to explain cancer, treatment and its side effects through language choices and employing visual aids such as drawings, metaphors and relatable analogies. (3) *Obtain support* from Aboriginal and Torres Strait Islander staff and patient escorts who can assist in communication. (4) *Consider culture* which involves collective decision making, strong connection to country and community, with cultural obligations and a unique understanding of cancer. (5) *Anticipate the contextual complexities* of conflicts between Western medicine and Aboriginal culture, practitioner bias and difficulty maintaining contact with patients. (6) *Develop personal qualities of good communicators*, including being patient-centred, showing respect, patience, empathy and honesty.

Conclusion These insights will help foster more positive interactions with the health system and promote optimal outcomes for Aboriginal and Torres Strait Islander people with cancer.

Keywords Cancer · Communication · Aboriginal and Torres Strait Islander · Qualitative · Patient education

Introduction

There are known disparities in cancer outcomes between Aboriginal and Torres Strait Islander and non-Aboriginal Australians, with a 5-year survival rate of 48% compared to 59% [1]. To help address this, Cancer Australia developed an optimal care pathway for Aboriginal and Torres Strait Islander people in consultation with their community, with communication identified as a principal component needed to improve care and outcomes [2].

The authors argue that appropriate communication will assist Aboriginal and Torres Strait Islander people to respond more effectively to a disease with a stigma that in the past has had a negative effect on individuals' uptake of clinical care in a timely manner.

Barriers to Aboriginal and Torres Strait Islander people engaging in cancer treatment vary, but may include

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perceptions of cancer as a ‘death sentence’, as contagious, as due to ‘payback’ or sorcery or inappropriate behaviour and/or as shameful [3].

To improve outcomes, it is essential that cancer and its treatment be explained to Aboriginal and Torres Strait Islander patients and their families and communities in ways that support understanding and facilitate informed treatment decision making. Approaches such as plain language without medical jargon, different styles such as story telling and use of illustrations have been suggested [4, 5].

To gain deeper insights into successful strategies for communicating about cancer and its treatment, we conducted semi-structured interviews with healthcare providers who regularly communicate with Aboriginal and Torres Strait Islander patients, including those from remote as well as non-remote areas. As participants represented several disciplines across two states, individual interviews rather than focus groups were conducted. This follows a successful methodology used to develop guidelines for communicating end-of-life issues to Australian patients with advanced illnesses [6]. Providers build experience of which strategies work over multiple consultations, providing a broader perspective than could be obtained from singular experiences of individual patients. The study’s aim was to identify practical tools and approaches that could form the basis of professional education for clinicians and, in turn, improve patient experiences and outcomes for Aboriginal and Torres Strait Islander people with cancer.

Methods

Participants

Twenty-three healthcare providers who were currently, or had previously, cared for Aboriginal and Torres Strait Islander people with cancer were recruited from Alan Walker Cancer Care Centre (Darwin) and from the authors’ personal and professional networks (Northern Territory, South Australia). Purposive sampling (based upon gender, Aboriginal status and type of health professional) was employed to ensure a wide range of perspectives [7] (Table 1).

Table 1 Participant demographics ($N = 23$)

Age (years)	
18–39	5
40–60	17
> 65	1
Sex	
Female	11
Male	12
Aboriginal or Torres Strait Islander	
Yes	5
No	18
Time working with Aboriginal and Torres Strait Islander patients	
< 1 year	1
1–5 years	9
6–10 years	4
> 10 years	9
Type of healthcare worker	
Aboriginal health worker	3
Nursing	6
Medical	7
Administration	5
Radiation therapy	1`
Public health	1
State/territory	
Northern territory	18
South Australia	5
Location of practice	
Urban	3
Rural	2
Remote	18

Procedure and materials

Ethics approval was granted by the University of South Australia Research Ethics Committee and the Human Research Ethics Committee of the Northern Territory Department of Health and Menzies School of Health Research. The study was part of the Centre of Research Excellence “Discovering Indigenous Strategies to Improve Cancer Outcomes via Engagement, Research Translation and Training (DISCOVER-TT)” and benefited from the Centre’s advice and networks, as well as the involvement of an Aboriginal investigator (AC) throughout the study.

After participants provided written consent, semi-structured interviews were audio-recorded either in person or by phone. Topics covered are outlined in Table 2. The interview guide was developed from the literature and from the experience of working with Aboriginal patients of (IO) and Aboriginal co-author (AC). Interviews took place between 2016 and 2019.

Analyses

Thematic analysis using a bottom up, essentialist/realist approach was employed to analyse the data, once data saturation was reached [8]. NVivo 12 Plus software was used to organise the data. Participants’ descriptions of their experiences and realities were assessed as direct insights into these experiences and thematic meaning was generally situated at the semantic or surface level of the data. Three researchers

Table 2 Interview topics

- What have you learned about communication that you have put into practice?
- What do health professionals need to consider when communicating with Aboriginal patients?
- Do you have specific words or phrases that help with understanding?
- Do you have images or metaphors which aid understanding of cancer and its treatment?
- How do you ensure that patients have understood what they are told?
- Comment on non-verbal communication and Aboriginal patients
- How do you establish rapport and make patients feel safe?
- Do you think guidelines would help with communication?
- How do you discuss treatment options with your patients?
- What is an alternative to the language of probability and percentages to discuss risk?
- Do you need additional resources to aid communication?
- Do you think phone apps would aid health workers in communicating with their patients?
- What are the most important personal attributes of health workers needed to work with Aboriginal patients?
- What is the best way for health workers to overcome racism-related barriers?

(KMG, IO, KS) coded the data and reached full agreement (COREQ Supplementary Table 1).

Results

The predominant disciplines of the 23 health professionals interviewed were nursing (6), medicine (7), Administration 5, Aboriginal health (3), radiation therapy (1) and public health (1). Twelve were female, 11 were male, with five identifying as Aboriginal or Torres Strait Islander (Table 1).

Six major themes emerged from the interviews; these are shown in Table 3 and illustrated below with example quotes (for more extensive quotes see Supplementary Table 2).

(1) *Create a safe environment/engender trust/build rapport*

The physical environment should be considered, for example sitting outside, or near a window. Videoconferencing to avoid travel may be appropriate especially for involving the patient's family and community. When travel is required, the practical issues of transport, accommodation, diet, finances and emotional support need to be addressed.

In the consultation, allow enough time for interpretation of the information. Avoid assumptions about how the patients are interpreting what is happening, what has been understood and what they want. Instead, pay attention to observable elements, such as non-verbals indicating distress or confusion, and ask patients what is acceptable, preferable and permissible to them (for example talking with the opposite sex).

> The other thing which is hard to explain how to do, is to create the illusion of having all the time in the world. And we have to do that not just with Indigenous patients, but most of our patients, because the last thing you want [for] your patient, who you are talking to [about] death and dying, [is to] feel that they're just another number on a conveyor belt. (…) a bit like a duck, over the water; you look serene and calm, but underneath you're paddling furiously (Participant (P)15, female nurse)

Build rapport with the patient by talking initially about what is important to them, such as their home and family. Finding connections between the health worker and the patient helps establish trust and the collaborative environment that is necessary before medical issues can be addressed.

> Family is so important in their life and family is being part of culture. So being able to talk to them and have a connection with them apart from just talking about cancer. So, it's not the first thing – cancer is not the first thing you talk about. Where are you from? Where am I from? You got grandkids? I've got grandkids. How many grannies you got? Immediately that rapport is met. Once they've got that then, then slowly you can talk about the cancer. (P14, female remote nurse)

(2) *Use specific strategies to explain cancer, and its treatment and side effects*

Using everyday terms and explanations which are tailored to the patient's context and devoid of medical jargon or colloquialisms, and avoiding statistics is perhaps self-evident. Providing advanced warning of upcoming sensitive or distressing topics allows patients to be mentally prepared, have the right support people present and avoids possible disengagement.

Table 3 Key themes regarding communication between cancer care professionals and Aboriginal and Torres Strait Islander patients

1. Create a safe environment/engender trust/build rapport
    - Avoid assumptions
    - Consider the physical environment
    - Consider gender (patient and provider)
    - Ask about home, family, what's important
    - Explain in detail what is happening and why; speak slowly and clearly; provide space for them to process and for answers and questions
    - Assess level of understanding via body language and/or paraphrasing
    - Allow for extra time, longer or multiple appointments
    - Schedule proximal appointments in consultation with the patient; don't keep them waiting; streamline the process
    - Ask what is or is not okay for the patient; ask permission
    - Consider and cater for the patient's current, individual circumstance/context/needs; provide logistical and moral support
    - Build relationship, find connections
    - Pay attention to/use non-verbal communication
2. **Use specific strategies to explain cancer, and treatment and side effects**
    - Visual aids
    - Simple/straightforward/appropriate language/communication
    - Metaphors
    - Avoid statistics
    - Repetition, reinforcement, persistence, consistency
    - Ideas/recommendations/suggestions for future interventions/ strategies/aids/tools/resources
    - Collaborative approach with patient; allow their needs to shape the treatment process
    - Coherence/cooperation/teamwork/coordination between professionals
    - Video/conference calls with family or community; telehealth
    - Warning about upcoming difficult subjects
3. **Obtain support from people who can assist in communication**
    - Interpreters
    - Aboriginal Liaison Officers
    - Aboriginal Health Workers
    - Patient escorts
    - Education about and/or exposure to/involvement in culture and community
4. **Consider culture**
    - Collective decision making
    - Connection to country/community/family
    - Cultural obligations/community roles that supersede treatment
    - Unique understanding of cancer/illness/treatment
5. **Anticipate/be aware of contextual complexities**
    - Many languages/dialects
    - Historical contexts influencing patient experience/attitudes/trust/fear
    - Disappearing/disengagement/ 'non-compliance'
    - Ethical conflicts between Western medical practice and Aboriginal culture
    - Difficulty in maintaining contact with patients
    - Different worldview hinders communication
    - Late-stage presentation results in more challenging subjects of communication
    - People may not mean what they say
    - Practitioner bias/attitude
6. **Develop good personal communication qualities**
    - Respect
    - Patience
    - Empathy/compassion/kindness
    - Person-centred/interest in the individual/listening/willing to engage
    - Honest/frank/forthright/genuine
    - Friendly, personable

> Make this simple and by simple, it means, yeah, you need to use simple words and related to other known concepts, but what they don't want is to be fobbed off with incorrect childish sort of concepts. (P18, Female, remote nurse)

Using visual aids, either scans, drawings or photos, promotes understanding. Metaphors and relatable analogies may also assist. For example, cancer was sometimes characterised as like an abandoned car in the desert (a familiar sight in northern Australia) where the body may look intact from a distance, but is rusted out inside. Another common analogy was a tree with roots spreading underground. A radiation oncologist used the example of pulling up weeds but then having to kill the roots to stop them resprouting in the next rain, to explain adjuvant radiotherapy after surgical removal of a tumour. Blocked pipes or dammed creeks were other examples of familiar concepts that are employed to successfully explain cancer and its symptoms.

> …the body is like a dot painting and so there are – it is more of a central Australian perspective when we talk, but there is a whole and it is made up of a lot of small parts which if you look very closely are all individual and all separate from one other and those are cells. So if there is an area of a dot painting that is behaving differently from the rest of the dot painting then that is a – that is similar to the way that cancer behaves… (P12, male remote medical oncologist)

In addition, assess the level of understanding of information by asking patients to explain what it means to them. Repetition of information using alternative means (e.g. images) and/or paraphrasing can also be helpful.

In addition to fostering a collaborative approach with patients providing ideas of what would aid effective communication for future consults, health workers must communicate well with each other to avoid providing conflicting information to patients and to help each other reinforce key concepts.

(3) *Obtain support from people who can assist in communication*

For those practitioners who will regularly provide services to Aboriginal and Torres Strait Islander patients, cultural training and visits to their communities are highly desirable to help understand their communication and logistical needs and allow the community to build trust with the practitioner. Involving Aboriginal Health Workers or Aboriginal Liaison Officers and patient escorts can help in successfully conveying information about cancer, necessary for patients to make informed treatment choices.

> [It's] really critically important to use Aboriginal Liaison Officers and/or interpreters and in being able to convey that information (P4, male urban medical oncologist)

However, patients' preferences should be carefully explored before engaging others, and where possible, it is usually best to use an unrelated Aboriginal medical interpreter.

There is no discussion to be had with someone that can't understand what you're saying. It's unsafe and it's bad practice and it happens too much. I think it's important for all cancer patients to have a long and healthy discussion with their oncologist, with the aid of interpreter if they don't understand English. (P2, female oncology nurse).

(4) *Consider culture*

Interviews underscored the need to understand Aboriginal and Torres Strait Islander beliefs in relation to illness, cancer and treatment. The causes of cancer may be ascribed to curses or magic or inappropriate behaviour, so a diagnosis may be a source of shame. Perceptions that cancer is a death sentence may result in not seeking medical help; late presentation and poor treatment adherence can produce poor outcomes, thus perpetuating this belief. In terms of treatment, there may be a strong desire to incorporate traditional remedies such as bush medicine.

> You're an individual. Aboriginal people are a collective. So, what is best for the community outweighs the individuals. (P16, female remote Aboriginal Liaison Officer)

Strong connections to country, community and family can make being distanced from them when sick distressing for individuals, and problematic with regard to accessing optimal cancer care. Fulfilling roles in the community (for example responsibility for taking part in Sorry Business) is often considered more important than an individual presenting for treatment if the two clash.

> …understanding that part of that Aboriginal wellbeing is their spirituality and connection to the Country (…). And if you're not there, you can't physically connect to Country, so it becomes quite an unhealthy situation, and people want to go home. (P5, male medical oncologist)

(5) *Anticipate/be aware of contextual complexities*

The context of communication is important. Health workers recognised that they may bring biases and unhelpful attitudes into consultations because of past experiences, misunderstandings, fear or ignorance of culture or beliefs. Likewise, historical contexts may influence Aboriginal and Torres Strait Islander people's attitudes. Trust may be low because of historical wrongs such as the Stolen Generations or fear may result from more recent experiences of discrimination by non-Aboriginal Australians.

> Sometimes people would come down here and they would die in hospital and it would be very traumatic for everybody, and the staff are watching these people cry and be really upset and not be able to talk to them in the same language, so that's very distressing for everybody. (P14, female remote nurse)

Late-stage presentations of Aboriginal and Torres Strait Islander people with cancer, resulting in poorer outcomes, can compound negative attitudes.

> There's a lack of trust and a fearing of the hospital, so people present late, when they present late, they then die, and the cycle goes on and on. (P18, female nurse)

In addition, there are conflicts between Western medicine, ethics and law and Aboriginal culture, priorities and law. The individual autonomy and privacy central to Western medical practice may conflict with cultural norms, which may require collective decision making as a family, or by community members with traditional authority.

As with other patients, different worldviews may mean that while Aboriginal and Torres Strait Islander patients may understand the Western concept of cancer, they may accord it different significance. Communication is complex, as Aboriginal and Torres Strait Islanders include diverse cultural groups with many languages and dialects, and patients may indicate understanding and agreement as a strategy to avoid conflict, embarrassment or discomfort being labelled as ignorant.

Developing alternative avenues of maintaining contact with patients is important, as some patients may share or swap their phones, live remotely outside towns "in the long grass" or have no fixed address. Sometimes, this results in non-completion of treatment or discontinuation of medication. A preference not to discuss certain matters may also lead patients to leave town.

(6) *Develop good personal communication qualities*

Participants also consistently identified the qualities of successful communicators.

> So it's all goes back to acknowledgement. The fact that in their life and in that small moment of disaster and mayhem, they're acknowledged as a person (P1, male remote Aboriginal health practitioner)

The importance of being person-centred and displaying a genuine interest in patients by being patient and showing respect were emphasised. Displaying empathy and honesty was also viewed as important.

> Try and somehow put yourself in their position, if you were a person that couldn't speak English and you were trying to be told around the fact that you've got this terrible disease or something that potentially is going to have a huge impact on your life, how would you feel? (P2, male, Torres Strait Islander Aboriginal Health Practitioner) .

A critical component identified as part of being a good communicator was the need for personal reflection and the development of self-awareness.

Discussion

This study identified communication strategies, approaches and practical tools used successfully by healthcare providers who regularly communicate about cancer care with Aboriginal and Torres Strait Islander patients, particularly those from remote communities, but likely to be applicable more broadly.

A major finding is the need to consider the cultural context of a cancer consultation. The strong connection with country, family and community which often forms identity can be a cause of great discomfort and/or conflict when Aboriginal and Torres Strait Islander patients are separated from them for medical care [3, 9]. However, awareness of this can assist in finding ways to maintain connection, within the constraints of treatment protocols. The past history of harmful contact between Aboriginal and non-Aboriginal Australians, such as the Stolen Generations, contributes to an attitude of mistrust, which is exacerbated by a system which discounts concepts outside the Western biomedical model of disease and treatment [4, 9].

The cultural concept of cancer itself was raised as having a bearing on communication. Not only can views such as the causation of cancer being a punishment or a result of magic and a cause of shame make the offer of surgery, radiotherapy and chemotherapy seem misplaced, but an ingrained view that equates cancer to a death sentence must be confronted appropriately to promote informed treatment choices [3, 5]. To understand beliefs about cancer from the perspective of Aboriginal and Torres Strait Islander people, other studies have suggested using photovoice and yarning circles to capture images and stories that represent cancer beliefs [5, 10, 11].

The importance of creating a safe environment for Aboriginal and Torres Strait Islanders to have conversations about cancer emerged as a strong theme in the data. Previous investigators have stressed that a major component of achieving this is care co-ordination and navigation of patients through an unfamiliar health system [12]. Coordination must include logistics of travel and accommodation. There is a strong need to have access to an Aboriginal health care provider, particularly if family cannot accompany a patient [13]. If needed, Aboriginal interpreters should be used whenever possible, even with family members present [14, 15].

What healthcare workers told us about patient consultations reflected ideal communication practices that should be employed broadly. Conversations should be centred on patients and what they want to know, with regular checking on what they understand and paraphrasing to avoid medical jargon [3, 12]. Our study highlights specific illustrations that have been used to successfully explain cancer and its treatment by experienced healthcare workers.

This study was limited to healthcare providers in Northern Territory and South Australia. It is unclear whether results would be similar elsewhere, in states with a higher percentage of Aboriginal patients from urban areas, or if patients' views would be similar to providers'. A further study interviewing Aboriginal patients would provide a useful complement to our findings.

The optimal care pathways which highlight communication need to be implemented [2]. The next step for this research is to create a teaching tool for health trainees, based on these insights, then testing it to see how well it equips workers to communicate effectively with Aboriginal and Torres Strait Islander patients with cancer, with the goal of improving their experiences with the healthcare system, and ultimately achieving better outcomes. It may also be useful to explore adaptation of question prompt lists, which have improved satisfaction with cancer consultations for other patients, as well as trialling information in digital form and further exploring remote communication by video conferencing and virtual reality, as there is evidence that these may prove acceptable and useful in remote regions for cancer management [16, 17].

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Data availability Data will be stored at University of South Australia for 15 years and available on request to the corresponding author.

Code availability Not applicable.

Declarations

Ethics approval Ethics approval was granted by the University of South Australia Research Ethics Committee and the Human Research Ethics Committee of the Northern Territory Department of Health and Menzies School of Health Research, and we certify that the study was performed in accordance with the ethical standards as laid down in the 1964 Declaration of Helsinki and its later amendments or comparable ethical standards.

Consent to participate Participants provided written consent to semi-structured interviews either in person or by phone and to those interviews being audio-recorded.

Consent for publication All authors and participants agreed to the publication of this paper.

Conflicts of interest The authors declare no competing interests.

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